

## ISSUE BRIEF

**Outcome # 1: Families of children with special health care needs will participate in decision making at all levels and are satisfied with the services they receive.**

*Michigan Department  
of Community Health*



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### **CHILDREN'S SPECIAL HEALTH CARE SERVICES STRATEGIC PLANNING 2008**

This background brief presents an overview of the **family participation** status for children and youth with special health care needs in Michigan. It has been prepared as a step in assessing the readiness, capacity, and barriers to a fuller implementation of family participation for children and youth with special health care needs (CYSHCN) in Michigan. Members of the **Children's Special Health Services Advisory Committee (CAC) and other partners** have compiled this brief to document the current status of family participation activity in both the U.S. and Michigan. This brief was developed as background material in preparation for the April 16 and 17, 2008 Michigan CYSHCN Strategic Planning Meeting. The meeting will result in a five year strategic plan. The overarching goal is to address for Michigan the 10-year Action Plan to Achieve Community-based Service Systems for Children and Youth with Special Health Care Needs and Their Families (U.S. Department of Health and Human Services, 2001). The focus of the CSHCS Strategic Plan is on assessing Michigan's current status of reaching the 2010 outcomes for CYSHCN, exploring strategies with key stakeholders from across the state to achieve these outcomes and in developing a prioritized five year plan to get us there. This brief is specific to the federal Maternal and Child Health Bureau Outcome #1: **Families of children with special health care needs will participate in decision making at all levels and are satisfied with the services they receive.**

# Family Participation

## Background

*The 2010 Action Plan for Children with Special Health Care Needs (CSHCN)* is a ten-year plan developed and promoted by the Maternal and Child Health Bureau (MCHB) in the Health Resources and Services Administration of the U.S. Department of Health and Human Services, and is endorsed by the American Academy of Pediatrics (AAP), Family Voices, the March of Dimes and over 50 other national organizations.

The Action Plan includes the specific outcome of family participation for all children with special health care needs by 2010. Work on this outcome is proceeding at both the state and national levels. At the present time, the definition for CYSHCN by MCHB and Michigan CSHCS do not fully coincide (see box). Michigan's CSHCS program provides medical and support services to eligible children. Due to budget constraints CSHCS cannot currently open up eligibility for medical care and treatment. The CSHCS program can, however, provide education and outreach to the broader CYSHCN population.

The document, *Healthy People 2010*, offers a set of health outcomes for the nation and reflects current health planning at the national level. The nation's health plan recognizes the key to improving care for CYSHCN lies in a systems approach to organizing and delivering services. Healthy People 2010 objective 16.23 is to "increase the proportion of states and territories that have service systems for children with special health care needs." Achieving this objective has been further defined by the federal MCHB as accomplishing six core outcomes (USDHHS, 2001):

1. **Families of children with special health care needs will participate in decision making at all levels and will be satisfied with the services they receive.**
2. All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
3. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
4. All children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

This Issue Brief focuses specifically on Outcome #1.

### Definition:

#### Children and Youth with Special Health Care Needs

##### National (MCHB)

Children and youth who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

##### Michigan CSHCS

Michigan's CSHCS eligibility criteria for children and youth focuses almost exclusively on physical health conditions and services provided by pediatric sub-specialists.

## The Michigan Story

Michigan has a long and proud history of making children with special needs a priority, dating back to the late 1800's when organized state-run services first were made available to "crippled children." In more recent history, the focus of the program has been medical care, treatment and support services for eligible children and some adults with one or more of approximately 2,500 physical-health-related diagnoses. The treatment and supports that the program provides must be specific to the qualifying condition(s). Except in unusual circumstances, CSHCS focuses on the services provided by pediatric or other sub-specialists and does NOT cover primary care services or providers unless they directly relate to the qualifying condition (e.g. pneumococcal vaccine covered for a child with Sickle Cell Disease, or a urinalysis ordered by the local pediatrician for a child with kidney disease whose specialist is 400 miles away).

For more than two decades, Michigan's CSHCS (Title V) program has earned national recognition for the way family-centered care is woven into all facets of its operations. Notably, CSHCS includes a parent of a child with special needs on its management team. The impact is that "the family point of view" influences all CSHCS policies, procedures, communications, and day-to-day operations.

The CSHCS division works collaboratively with the Family Center for Youth and Children with Special Health Care Needs (Family Center). The Family Center is a section of the division that provides training, support, and family partnerships for CSHCS. The driving force of the Family Center is a solid commitment to family-centered, culturally competent, community-based, coordinated care for children and families. The Family Center has been an integral part of Michigan's Title V program since its launch in 1988. Through September 2005 the Family Center was known as the Parent Participation Program. The name change reflects the Center's broad scope.

The Family Center engages in partnerships with CSHCS enrolled families to shape policy. Through the Family Support Network of Michigan, a Family Center program, the Family Center provides emotional support and information statewide

**Michigan's Family-to-Family Health Information and Education Center (F2FHIEC)** is funded by the Centers for Medicaid and Medicare Services (CMS) through a Real Choice Systems Change Grant. Real Choice Systems Change Grants were created on February 1, 2001 as part of President Bush's New Freedom Initiative, a nationwide effort to remove barriers for people with disabilities. Michigan's F2FHIEC began on 10/1/05 and will be funded until 9/30/08.

to families of children with special health care needs. The Family Center is also the lead agency for Michigan's Family-to-Family Health Education Center (F2FHIEC), which provides families of CYSHCN with information, education and parent-to-parent support through on-site and on-line trainings, coordinated outreach products and website linkages with 30 state partner agencies and organizations.

Acknowledgement of the role of families as critical partners with professionals in program and policy activities has been an

important shift in health care delivery and is now well accepted in many spheres. While the Maternal and Child Health Bureau (MCHB) has referred to the philosophy of family-centered care as relevant for all families, it was not until 2002 that the MCHB Strategic Plan included the phrase, “to promote and support the development of family-centered, culturally competent, community-based systems of care nationwide for CSHCN, *and the entire MCH population.*”

CSHCS has a partnership with local health departments (LHDs) to provide a community-based “home” for the program. Each LHD in the state has a CSHCS office with staff support, which may include a public health nurse and a community representative. The amount of time and staff committed each week to providing CSHCS services varies greatly and depends upon state and local funding structures. Family participation in the community occurs at the local health department level.

## Michigan and National Data

### *Family Satisfaction*

The National Survey of CYSHCN (2005/2006) is a national telephone survey. Participants are those who report having a child with a special need. Persons beyond those with Michigan CSHCS coverage or eligibility for their children were interviewed. The National Survey reported the following positive responses:

- 87.8% : “Doctors usually or always made family feel like a partner;” and
- 56.4%: “Family was very satisfied with services received.”

A family satisfaction survey was administered to families in a partnership between CSHCS and the Family Center. Surveys were sent out in spring, 2006. Returned responses indicated:

- 80.8% of respondents contacted their local health department;
- 92.6% indicated they were treated with courtesy and respect; and
- 92.2 % were satisfied to extremely satisfied with CSHCS staff.

### *Cultural and Linguistic Competence in Family Supports*

Given the great diversity in the country and in Michigan, providing family supports that respect the culture, values, preferences, and needs of each family presents many challenges. Organizations providing and coordinating family supports are faced with changing demographics and a need to understand and address a multiplicity of cultures, languages, and values in the families with whom they partner. Because of the diverse population and many non-English speaking households, the **Family Phone Line** utilizes the AT&T Language Line for translation services. In 2006 the Family Center had 67 requests; 43 were Spanish and the rest were a variety of other languages. The Family Phone Line also participated in six relay calls for individuals with hearing impairment.

#### Michigan Population 2006

- White: 79.5%
- Black: 14.1%
- Asian: 2.3%
- Hispanic: 3.9%

### *Communication Accommodations*

Linguistic competence also extends to ensuring that individuals with disabilities can effectively communicate within service delivery or family support systems. Accommodations for individuals with sensory impairments (e.g., sign interpreters, large print, or Braille materials), motor and expressive communication impairments (e.g., extra time to express thoughts and assistive technology), and cognitive impairments (e.g., information expressed at appropriate levels, and use of pictures and demonstrations) are vital and require aspects of linguistic competence. CSHCS and the Family Center provide these accommodations upon request at our trainings and community meetings.

### **Personal Narrative**

Responses through the Michigan CSHCS family satisfaction survey demonstrated that families were highly satisfied with services from the local health departments. Comments from families were:

- ★ "They are very helpful in all areas."
- ★ "CSHCS is a great program. We moved from another state where getting assistance was a nightmare."
- ★ "Thank you for sending this survey. This program has been so helpful in helping us care for our daughter."
- ★ "The assurance that if my daughter needs, then they will be there."
- ★ "It is always a pleasure to meet kind, loving & caring individuals considering the world today. Thanks again."
- ★ "Thank Goodness for CSHCS."

Over the past 11 years Michigan has been providing support to siblings by holding the conference **Relatively Speaking**. It has been clear from the past evaluations that there is a need for continued support of this statewide conference. Each year when asked if you would attend another conference like this, 100% say "Yes." It is also clear that siblings benefit from the inclusion of all family members.

One family stated *"the interaction with other families and networking is essential to survival. Networking with other parents, relaxation and enjoyment through interaction, and seeing our five year old grow years in one weekend."*

### **Current Status in Michigan**

Michigan's Family Center is an excellent resource for obtaining family input and determining problem areas in need of being addressed. Based on the large number of calls, **an average of 2,260 monthly**, the Family Center receives, CSHCS keeps abreast of current and rising issues in the families of children with special needs "community."

Michigan CSHCS has consistently had a very high rating regarding family participation in program and policy activities. CSHCS monitors client and family satisfaction through the types of calls received to the Family Phone Line and through returned postcards from the FSN brochure and the CSHCS Family Guide.

The Family Center has worked with CSHCS to **survey family satisfaction** in five Michigan counties for quality improvement purposes. CSHCS works collaboratively with the Family Center to develop, use and analyze the results of the satisfaction survey. In addition, Michigan includes features related to physician partnering with families of CYSHCN while developing the medical home model, and incorporates aspects of family-centered care and family inclusion as partners in the decision making process.

The Family Center provides consultation to the Michigan Title V program. Other services the Family Center provides are:

- **Family Phone Line**
  - Information on CSHCS and other resources;
  - Transfer calls for families to reach providers or CSHCS staff; and
  - Language Line to facilitate communication for non-English speaking consumers.
- **Family Support Network**
  - Family “matches” between families dealing with similar circumstances regarding the child with special needs; and
  - Emotional support to parents, grandparents, siblings and other caregivers of children with special needs.
- A **biennial conference for siblings** of children with special needs called *Relatively Speaking*.
- **Parent scholarships** to attend conferences related to the diagnosis, care, or medical treatment of their children with special needs.
- **Youth scholarships** to attend conferences related to their diagnosis, care, or medical treatment.
- **In-service training** for families, Pediatric Regional Centers, Medicaid HMOs, local health departments, and various agencies.
- **Family participation** on advisory boards and focus groups.
- **Family-friendly scheduling** to coordinate opportunities with the families' busy schedules, i.e., weekend and evening meetings, etc.
- **Supports**, e.g., translators, child care, stipends, mileage.

CSHCS has other ways families participate in decision making. The **CSHCS Advisory Committee** serves in an official advisory capacity for the division and provides input in all matters, including policy, budget, and operations. The advisory committee is comprised of professionals and families. In this role, family members sit directly with professionals in the decision making processes.

### Challenges/Barriers

There are many challenges and barriers to hamper full family participation in the decision making process. These include:

1. Lack of administrators in Michigan's system to embrace family-centered values and, thereby, to apply them in the decision making process.
  - a. This effects services offered to families including the lack of mandatory training on family-centered care elements and subsequent lack of

- internalization of family-centered care values -- for elected officials, nurses, physicians and other providers, social workers, health care administrators.
- b. This also compounds the challenge of funding for regional staffing and coordinated statewide initiatives to break the barriers. There needs to be an effective vehicle for family participation on an administrative level beyond local “advisory” boards, such as paid parent consultant positions at a level guaranteeing genuine opportunity and influence to impact systems.
2. There is a need to develop distinct Michigan networks, linked to all levels of the healthcare system, for fathers and for grandparents of children with special needs, many of whom are primary caregivers.
    - a. Current best practices focus on maternal perspectives and service needs.
    - b. The beginning of expansion to its traditional scope is the CSCHS fairly recent attention to youth in transition.
  3. The availability of information and effective tools is a challenge for full family participation. The need for information in the native languages of foreign-born individuals and communication accommodations (e.g., large print, Braille, pictures, etc.) for persons with sensory and developmental disabilities is also a barrier to full integration of all families into the decision making process. Organizational policies are needed that ensure information about the program, access to the program, and services are available in the languages spoken by families in the area served.
  4. There is a need for organizational policies and structures that:
    - a. Support community engagement, including periodic review of local demographics to determine current and emergent population trends; and
    - b. Delineate community and consumer participation in planning, implementing, and evaluating the delivery of services and supports. When resources are limited it is essential to engage communities to set policies to determine how such resources are administered.
  5. Services available to families are dependent on where they live.
  6. There is great variability at the local level of including family input.
  7. There is a lack of standard for delivering family-centered care, and informing families.
  8. Varying buy-in from health care providers on family-centered care is a problem.
  9. Public Health Code hasn’t been revised to include the requirement of family centered care.
  10. There is not much allowance for family choice in health care and service delivery.

## **Strengths/Opportunities for Improvement**

1. There are many family-centered committee work efforts at children's hospitals.
2. The opportunity to connect with Family Voices.
3. The Family Center provides support for families to attend conferences.
4. Families are included in many areas of CSHCS and Medicaid.
5. Data and evidence based information is available to show family participation results in better services.
6. Family Centered advocacy is starting to have an effect in Medicaid policy.
7. The Family Center shares a family consultant position with the genetics program
8. There is a mechanism in place for outreach to families.
10. The Family Centered movement has a partner in the MI AAP. There are important champions physician partners
11. The Family Center has compassionate – caring staff.
12. F2FHIEC is going statewide and can fit into a regional system of care.
13. Uses of Doc site – include family child information, web based, family access.
14. Transition work including youth in family centered discussions.

## **Prioritized Recommendations (outcomes from Strategic Planning)**

- \*1. Collaborate with partners and build coalitions to assure that all families have full access to consistent and complete information on program benefits, information on the benefits of family partnership; conduct outreach to fathers, grandparents, youth and diverse populations, improve shared awareness of benefits of partnering organizations, develop, translate, and communicate information in multiple formats, languages, and literacy levels  
Sub priority: Send letters to families with infants on the birth defect registry (18 votes)
- \*2. New regional structures are required to have family advisories that will develop guidance to prepare, recruit and engage families to become advisors. Composition of family advisory structure will be reflective of community served and inclusive of youth. Each region will have a face-to-face family liaison. Provide minimal standards for financial support for family participation.



3. Assure accountability of local efforts to achieve collaboration, partnership, and outreach. Use surveys and focus groups to measure and improve satisfaction levels. Require annual reporting on performance towards achieving criteria/objectives articulated in the federal goal
4. Implementing statewide, regional, and local family leadership training

\*High priority as determined by participants at the Strategic Planning session.